



Family Voices of Illinois

The Arc of Illinois

Family to Family Health Information Center

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To: Health and Medicine Policy Research Group
From: The Arc of Illinois Family to Family Health Information Center, Family Voices Illinois
Re: Comments on Medicaid 1115 Draft Application
Date: January 21, 2014

This is The Arc of Illinois Family to Family Health Information Center's second set of recommendations pertaining to the Illinois Department of Healthcare and Family Services Draft Application for an 1115 Medicaid Waiver.

These comments are based upon our extensive experience in providing statewide information, referral and training services to thousands of families and professionals regarding children and youth with special health care needs, disabilities and chronic illness.

1. Delivery System Transformation

a. Demonstration Eligibility and Enrollment:

- i. Ensure that EPSDT regulations are applied to all enrollees up to age 21, regardless of their status as a "child" up to age 18, or a "youth" age 18-21.
- ii. Waive parental income for all eligible child waiver participants. Currently only two of the six 1915(c) waivers which serve children waive parental income.
- iii. Fully Implement the Medically Needy eligibility path to waiver eligibility, and include a requirement for Medicaid spenddowns to be calculated, monitored and tracked for all applicants with special needs/chronic illnesses and/or disabilities who are initially deemed to be "over income" for Medicaid.

b. Benefits - Add the following benefits to the listing of Long Term Services and supports:

- i. Psychiatry to be included with Behavioral Services
- ii. Medical Day Care for children, youth and adults
- iii. Private duty in-home nursing for children and adults
- iv. Registered dietician services for children and adults
- v. Formal caregiver training – across all categories of paid caregivers - including but not limited to, physical disability, nutrition, first-aid, CPR and Universal Precautions, behavioral health, assistive technology,

communication, and other needs as indicated on an individual's plan of care.

2. Population Health

- a. Ensure that all health care provider facilities are fully accessible to children and adults with disabilities, according to the regulations of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act.
Accommodations to include, but not be limited to:
 - i. Facilities accessible to persons of all ages/sizes who use mobility devices
 - ii. Facilities to include waiting areas for children and adults with autism spectrum disorders and other developmental disabilities that are congruent with their sensory needs
 - iii. Accessible diaper-changing areas for non-ambulatory children and adults
 - iv. Accessible scales for children and adults unable to sit or stand on a regular scale
 - v. Training on meeting the needs of patients of all ages who have intellectual and developmental disabilities.
- b. Address food insecurity with measures specific to children with special health care needs. Accommodations to include, but not be limited to:
 - i. Assure that children with special health care needs that affect their nutritional status are able to continue their WIC enrollment until their 5th birthday. Monitor and track their continued enrollment.
 - ii. Include School Lunch Program eligibility and enrollment of part of the IEP (Individualized Education Plan) and 504 Plan process statewide.
 - iii. Provide technical assistance to medical providers and school district personnel regarding addressing special nutrition and/or feeding needs. Monitor and track implementation.
- c. Establish care coordination programs for both children and adults with complex medical needs, including those with developmental disabilities
- d. Utilize telepsychiatry for follow-up care only, not in lieu of in-office appointments.

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